

In CONTROL

A Medical Education Institute/Life Options Publication

VOL. 3 | NO. 2
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How to Use *In Control*

Each issue of *In Control* offers background, tips, and patient education material on one topic that is important to living well with kidney disease. The 2-in-1 format of *In Control* is designed to make it easy to find the information and share it with your patients.

For you, there are 4 pages of professional content (pages S1, S2, S7, and S8), along with practical tips for putting key concepts into practice.

For your patients, there are 4 pages (S3–S6) of easy-to-read information. There's also a quiz patients can use to test their knowledge.

We encourage you to make copies of *In Control*. Use it to supplement your own education materials, and call us at (800) 468-7777 if you want to reprint an article. Help your patients get “in control” of their kidney disease!

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Kidney School™: Unique CKD Education Tool

Renal professionals rely on a variety of resources to help educate stage 3–5 chronic kidney disease (CKD) patients about kidney disease and its treatments. One resource, developed by Life Options, takes a unique approach—by helping patients educate themselves. Kidney School (www.kidneyschool.org), an interactive online learning center, focuses on self-management skills and attitudes, as well as facts.

Kidney School has 16 modules written at the 7th–9th grade level. Access is free, 24 hours a day. Each module covers one topic and can be completed in about 30 minutes. The online modules are tailored: each user has a unique experience and can print a *Personal Action Plan* at the end of a module for review, personal goal-setting, and a reminder of questions for the care team. PDF versions of each module can also be downloaded.

Since its launch in 2002, Kidney School has become the nation's largest CKD education program, with:

- 12,000+ unique visitors each month
- 35,000+ downloads per quarter
- 40,000+ referral postcard requests in 6 months

Research-based Design

Kidney School was created using research-based principles of adult

learning and tested with patients prior to launch. Because adult learners want to choose topics that interest them, Kidney School is modular so users can choose topics in any order they prefer. The reading level was matched to the educational status of U.S. dialysis patients (most are high school graduates);¹ adjusted downward by 3–5 grade levels in accordance with learning theory.² The type size is large enough for visually-impaired readers—and adjustable via any web browser—and each page is short enough to maintain a comfortable pace.

Expert Review

All Kidney School content was based on published research and reviewed by a multidisciplinary expert team. And, Kidney School has earned Health on the Net (HON) certification as a reliable, trustworthy source of health information for people with CKD.

Messages of Hope

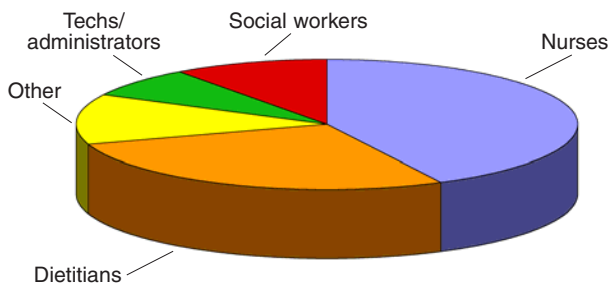
In addition to healthcare information, Kidney School includes key messages of hope and self-management. The importance of these messages has been established by research with long-term dialysis survivors, who actively self-manage their lives and their health.^{3,4} Kidney School encourages every patient to take part in positive self-management

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Survey Results: What We Learned About Kidney School™ Use

In March, 2006 we sent an online survey to 150 dialysis professionals who requested free Kidney School postcards. More than 25% responded. Here's what they told us:

Professions of Those Who Recommend Kidney School



Most Recommended Topics*

Treatment options	47%
Nutrition and fluids	44%
Living with CKD	36%
Kidneys: how they work	36%
Lab tests	31%
Coping with CKD	28%

* Total >100% due to multiple responses

Target Patient Groups*

Current dialysis patients	80%
New dialysis patients	75%
Family members	62.5%
Staff	57.5%
Predialysis patients	55%

Where Patients Use Kidney School*

At home	67.5%
Friend/family computer	27.5%
Library	20%
In clinic waiting room	7.5%
At dialysis station	5%

How Patients Benefit*

Increased knowledge	95%
More prepared for dialysis	56%
Less fear (of dialysis/future)	54%
Better diet and fluid control	54%
Informed treatment choice	46%
Improved attitude	44%
Take meds as prescribed	26%

Order Free Kidney School Postcards!

Order free Kidney School postcard handouts online at www.kidneyschool.org. You can give the two-sided

cards to patients and family members to let them know about Kidney School.

www.kidneyschool.org

A FREE web-based kidney disease learning center in sixteen 30-minute modules:

- Research-driven & reviewed by national experts
- Multiple interactive modules tailored to each user
- Easy to use – test your knowledge!

Developed by the award-winning Medical Education Institute, supported by LIFE OPTIONS

Each Kidney School™ module offers lively, easy-to-read content, a pre- and post-test, photos, graphics, patient quotes, a user evaluation, and a completion certificate. And each module creates a *Personal Action Plan* based on what you put in. Learn what you want when you want. Downloadable PDFs are available, too!

The 16 modules of Kidney School are:

Intro – Living Successfully with Kidney Disease	Module 10 – Getting Adequate Dialysis
Module 1 – Kidneys: How They Work, How They Fail, What You Can Do	Module 11 – Sexuality and Fertility
Module 2 – Treatment Options for Kidney Disease	Module 12 – Staying Active with Kidney Disease
Module 3 – Working with Your Healthcare Team	Module 13 – Heart Health, Blood Pressure, and Fluids
Module 4 – Following Your Treatment Plan	Module 14 – Patient Rights and Responsibilities
Module 5 – Coping with Kidney Disease	Module 15 – Alternative Remedies
Module 6 – Anemia and Kidney Disease	Module 16 – Long-term Effects of Kidney Disease
Module 7 – Understanding Kidney Lab Tests	
Module 8 – Vascular Access: A Lifetime for Dialysis	
Module 9 – Nutrition and Fluids for People on Dialysis	

www.kidneyschool.org

Life Options and Kidney School are supported by an unrestricted educational grant from **AMGEN**

Professionals: Earn CE credit on-line! 2 contact hours for Modules 1 & 2. Learn more at www.kidneyschool.org

This continuing nursing education activity was approved by the Minnesota Nurses Association Continuing Education Approval Program Committee, an accredited sponsor, by the American Nurses Credentialing Center's Commission on Accreditation.

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Reports from the Field: Kidney School in Action

Professionals rely on Kidney School to help them provide their patients with high-quality education. Here are reports about how some nurses, dietitians, and social workers use Kidney School:

Nurses

Valorie Paxton, RN, CNN, nurse educator for three DCI clinics in Missouri has referred her patients to Kidney School for 2 years. “I’ve been through the whole thing myself,” she said, “and I am very impressed.” Paxton uses the free postcards to make her patients—and colleagues—aware of Kidney School:

- Predialysis patients get a postcard in their education classes.
- Current patients and family members will find postcards in the lobby and on the bulletin board.
- Clinic staff can easily find the Kidney School URL on the postcard taped to her office door.

Paxton has printed all of the module PDFs and keeps them in a binder. She makes copies of individual modules or pages, as needed.

Lori Jewett, RN, dialysis coordinator at the Paul Gerry Dialysis Unit in Sayre, PA, is working on a systematic dialysis patient education program based on Kidney School. By the end of the year, nurses will go through Kidney School, module by module. Jewett believes this will help standardize patient education and ensure that all patients receive comprehensive information about CKD and dialysis. At present, her clinic has Kidney School bookmarked on laptop computers patients can use during dialysis. And, they include Kidney School postcards in the CKD education packets for predialysis patients.

Kay Chapman, RN and Morna Williams, RN, University of Utah, PD program nurses, refer predialysis patients to Kidney School as part of their dialysis options class, and again when they’ve completed PD training, putting special emphasis on modules that may be most pertinent based on needs assessments done during training. Finally, they use Kidney School at monthly PD clinic visits. “I might send home a module printout to reinforce something I’ve taught,” noted Williams. Chapman, on the other hand, will log onto the site while a PD patient is getting IV iron. “We’ll go through the module together,” she said.

Melinda Martin-Lester, BA, RN, CNN, Director of Regulatory Compliance for Renal Ventures Management, LLC, plans to include Kidney School information in a CKD kit she is preparing for physicians. “We want to provide a list of resources they can use to improve education,” she said, “and Kidney School is an excellent resource.” She uses Kidney School herself as a quick reference, and most recently, printed the *Staff Idea Guide* for her clinic managers.

Dietitians

Janine Neiwirth, RD, serves two DaVita dialysis clinics in Idaho. She has created a poster encouraging patients and families to access Kidney School. In addition, she uses Kidney School to help her provide state-mandated nutrition education to all new dialysis clinic employees. “It’s a big help,” she said, “and new hires often come to me with questions after they review the nutrition module.”

Melissa Krentzman, RD, Lithonia Dialysis in Decatur, GA, prints out the nutrition module for her patients. “For some it is the first time they’ve heard that there would be dietary restrictions,” she said. “The menus are particularly helpful because they are specific for diabetics, and different modalities.”

Social Workers

Evelina Martin, LCSW, MSSW, University Medical Center, Lubbock, TX, refers all her pre-transplant and transplant patients to Kidney School. “The modules are manageable size,” she said, “there’s a lot of information without too much length.” Lately, she has been using the *Sexuality and Fertility* module with post-transplant patients. “It helps in the discussions of relationship issues,” she noted.

Stacy Ervin, MSW, works for Satellite Dialysis in northern California. Like many other professionals, she uses Kidney School to orient new staff to working in a dialysis clinic. “It is user-friendly and easy-to-understand,” she said. “It gives new employees a perspective on what patients are living with.”

Susan Kreuter, LCSW, North Beach Dialysis Center, Miami, FL, finds that Kidney School helps her patients talk with their loved ones about kidney disease and dialysis. “I encourage patients who don’t have Internet access to ask their children or grandchildren to help them with Kidney School because it’s a way to get the family involved and opens the door to conversation.” If she prints one module, even patients without computers find a way to go on to more modules. “It wets their appetite,” she said. 🌐

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Kidney School™: Unique CKD Education Tool

activities (and avoid negative ones) and includes those messages in each module.

“We created Kidney School to provide the in-depth self-management information patients need to survive with CKD—in a format that would not create a burden for busy healthcare professionals,” explained Dori Schatell, MS, Life Options Program Director.

Proven Results

Individuals of all ages, races, and educational levels use Kidney School. Comments from those who complete the evaluation form at the end of each module have been overwhelmingly positive, and provide concrete evidence that Kidney School is meeting patients’ educational needs.

Overall satisfaction with Kidney School ranged from 92.2% to 96.9%, and users agreed that Kidney School was useful and included information they could apply in their lives.⁵ Perhaps most interesting, users with less education actually rated Kidney School significantly higher. These results suggest that Kidney School may have a positive impact on patients’ intent to self-manage, particularly among less educated and non-white users. 6

References

1. Schatell D, Wise M, Klicko K, Becker B. In-center hemodialysis patients’ use of the Internet in the United States: a national survey. *Am J Kid Dis* 2006 (in press).
2. Doak CC, Doak LG, Root JH. *Teaching Patients with Low Literacy Skills*, 2nd ed. Philadelphia, PA: JB Lippincott Company, 1996.
3. Curtin RB, Mapes DL. Health care management strategies of long-term dialysis survivors. *Neph Nurs J* 28(4):385-394, 2001.
4. Curtin RB, Sitter, DC, Schatell D, Chewning BA. Self-management, knowledge, and functioning and well-being of patients on hemodialysis. *Neph Nurs J* 31(4):378-387, 2004.
5. Schatell DR, Becker BN, Klicko K. Kidney School: user response to a web-based patient education program. *J Am Soc Nephrol* 14:Abstract, 2003.

38 No-Cost Ways to Use Kidney School™

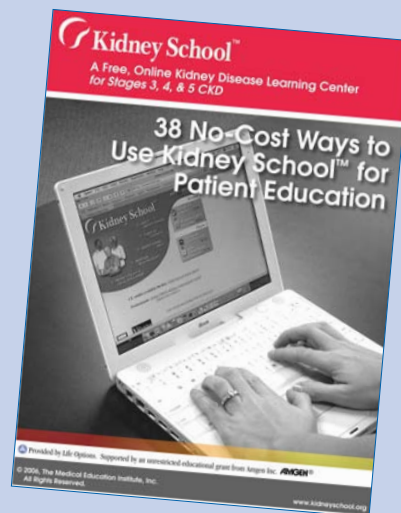
To help patient educators explore new ways to use Kidney School—and get the full benefit of this helpful online resource—Life Options developed an easy-to-use idea guide. The guide, entitled “38 No-Cost Ways to Use Kidney School for Patient Education,” was compiled from a variety of resources and reviewed by a multidisciplinary team of dialysis professionals.

Response to this new online resource has exceeded expectations. In just the first month, more than 3,700 copies of the 12-page guide were downloaded from www.kidneyschool.org.

In addition, excerpts from the guide were distributed by Mary Beth Callahan, MSW/ACSW-ACP, at her nephrology social work seminar at the NKF meeting in April, 2006.

There are many ways to use Kidney School—for different audiences, in different settings, and for different purposes. Using tips from the idea guide can help busy professionals address the educational needs of stage 3–5 CKD patients.

More than 41,000 Kidney School postcard handouts were also requested in 6 months (October–March). Clearly, dialysis professionals like Kidney School—and use it in many ways.



In Control

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In Patients **CONTROL**

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Kidney School™: Learn to Live Well on Dialysis

From lifestyle changes to medical choices, there is a lot to know when it comes to living with kidney disease! And, while it may be easy to give up control since you rely on so many people for care, learning as much as you can helps you take back control of your life.

Knowledge Is Power

Learning about kidney disease helps you recognize and report symptoms, decide what questions to ask, and begin to manage as many aspects of your care as possible. Studies have also shown that the more you know, the less fear you will have about the future.

This is where Kidney School comes in! Kidney School is an interactive, online learning program that can be found at www.kidneyschool.org. It's free, and was designed to help you learn what you need to know to understand kidney disease and make

good medical decisions—whether you are new to kidney disease or have been on dialysis for many years.

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Featured Topics

Kidney School covers a wide range of topics, conveniently listed in a table of contents—you can go right to the information you need! Kidney School topics include:

- Kidneys: how they work, how they fail, what you can do
- Treatment options
- Working with your healthcare team
- Following your treatment plan
- Coping
- Anemia
- Understanding kidney lab tests
- Vascular access
- Nutrition and fluids
- Getting adequate dialysis
- Sexuality and fertility
- Staying active
- Heart health and blood pressure
- Rights and responsibilities
- Alternative treatments

How to Use Kidney School

Kidney School is user-friendly and allows you to take in information at your own pace. Some of the features of Kidney School are outlined in the graphic on page P4.

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Kidney School Is Prime Course for Education

Fifty-five year old Linda has a favorite saying: “Live in knowledge, not in fear.” For Linda, Kidney School started her on the path to knowledge about her kidney disease—knowledge she now shares with new kidney patients.

A New Beginning

Linda’s kidney problems started 35 years ago with a series of bladder infections. “I was 21 and newly married,” Linda recalls. “I went to a urologist who said it was a birth defect and that I would eventually have kidney failure.” Linda took medication to keep the infections at bay, and was monitored with lab tests. It was during this time that Linda and her husband adopted a daughter, now 25.

For 25 years, Linda’s kidney problems were kept at bay. That all changed with



a visit to her doctor. “I went to the doctor for another health problem and mentioned that I was always feeling tired,” Linda reports. “My doctor ordered blood tests and found that my creatinine was very high.” Linda was referred to a nephrologist, who said that she would need to start dialysis within 6 months. “We continued to monitor my blood levels, and I didn’t start in-center hemodialysis for 2.5 years!”

Finding Kidney School

Linda started dialysis in March of 2002, and had concerns right away. “When you are first told you have kidney failure you think you can’t work or do anything—you think you are going to die,” Linda recalls. “I wasn’t sure I would live to see my first grandchild.”

Feeling hopeless, Linda went on-line to look for kidney support groups. “Many of the groups suggested I go to Kidney School,” Linda says. “I was depressed and thought I was alone—I didn’t know it was a common symptom until I went to Kidney School.”

Linda has found Kidney School to be “extremely helpful,” stating, “I can’t see how anyone would have any problems with the site or questions about what they’re reading, because the site is very clear and concise.” Linda especially likes the format of having a table of contents with modules listed by topic. “Right away you know where the answer to your question falls,” Linda relates. “There is no doubt in my mind that I would rate Kidney School #1 for kidney information.”

In 2005, armed with information, Linda started to consider home dialysis. “I really wanted to be able to go camping and didn’t want kidney failure to affect our lives too much,” Linda says. It was during this time that Linda received a kidney transplant.

The Need for Education

In addition to working as a receptionist at a veterinarian’s office, Linda works with the social worker at her dialysis center to educate new kidney patients. “We have come together to start a support group and offer new patient information kits,” Linda shares. “We are also putting together packets for physicians’ offices.” Recently, Linda started putting Kidney School cards in the new patient kits, stating, “Kidney School answers virtually every question about dialysis that I can think of! I appreciate that Life Options gives me the things I need for free.”

Linda is passionate about education for people with kidney disease. “I think you need to educate yourself so you can participate in decision-making,” Linda says. “Otherwise you won’t know if the decision being made is the right one for you. You need to know what’s going on.” Recalling her own experiences on dialysis before she became educated, Linda shares, “I just always assumed my blood work was okay since I didn’t hear otherwise—which is what most people do. Luckily I was fine, but I didn’t know enough to know what

the values meant or what I should look for.”

Linda says people often ask her why she pushes education so much. Linda’s answer: “Without education you can’t take control. And I know I feel powerful when I know what’s going on!” Linda has also made it her mission to get the word out about kidney disease to the general public. “You can find asthma and diabetes information in your doctor’s office, but nothing on kidney disease,” Linda explains.


“There is no doubt in my mind that I would rate Kidney School #1 for kidney information.”

“People aren’t aware about symptoms of kidney disease. If my doctor wasn’t wise enough to do a blood test when I said I was feeling tired,

I may not have known about my kidney problems until I was worse off!”

Sound Advice

Linda offers new kidney patients the following advice: “When you are new to kidney disease, don’t panic! Gather support people and as soon as the shock wears off, go to support groups and Kidney School.”

With her first grandchild due in October, Linda feels her life would be much different had she not educated herself about kidney disease. “I wouldn’t have realized I could do all this without Kidney School and other support sites,” Linda says. “Now I know the hopeless feeling isn’t necessary—you can live perfectly well with kidney disease and still live to see your first grandchild!” 

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Kidney School™: Learn to Live Well on Dialysis

Features of Kidney School...

The screenshot shows the 'Kidney School' website interface. At the top, there is a navigation bar with links for HOME, INDEX, PRIVACY POLICY, FURTHER READING, and HELP. The main content area is titled 'How kidneys work' and features a large, detailed anatomical diagram of a kidney with interactive blue buttons. Text on the page explains kidney function and provides links for further information and a Flash viewer plug-in. A 'GO AHEAD' button is also visible. Callouts from the surrounding text point to various elements: 'Detailed graphics and animations' points to the kidney diagram; 'Large type size' points to the main text; 'Interactive' points to the blue buttons on the diagram; 'Topic links, books, and resources' points to the top navigation bar; 'Informative, easy-to-read text' points to the introductory paragraph; and 'Helpful computer tips' points to the Flash viewer instructions.

Thousands of patients have used Kidney School, offering such feedback as:

"This is a magnificent, informative, well-written, and fun website. You are able to project such a personal feel and personal involvement. Thank you!"

"Kidney School takes some of the fear and confusion about kidney failure away and makes life a lot less stressful."

Computer Requirements

You need a computer to access Kidney School. If you don't have a computer at home, try the library. Or, ask a friend or relative to help you log on so you can use Kidney School. If no one you know

has a computer, ask a social worker or other health care staff member if they could print out a module for you.

You are the creator of your best possible health and life. Learning all you can at Kidney School is a great first step! ☺

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